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Barriers to Co-Designing Mobile Technology with Persons with Dementia and Their Carers

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Abstract. Mobile applications can be used to help manage different aspects of long-term illnesses but many are not designed to meet the specific needs of people with dementia or their carers. This case study explores the barriers experienced when co-producing a memory and reminiscence app. A focus group and interviews were conducted with patient/carer dyads, an occupational therapist, project manager and software engineer involved in the design of the app. Data was analysed thematically using the framework approach. Several limitations such as poor technical knowledge and skills, negative attitudes and inaccurate perceptions of people with dementia slowed down or changed how the mobile app was developed. Compromises also had to be made over the final design of the app. More research to explore how mobile apps are co-designed with patients is needed.

Keywords. Dementia; Alzheimer's disease; mobile technology; mobile app; co-design; co-creation; co-production; engagement

1. Introduction

Dementia is becoming an important public health priority due to growing numbers of older adults and degenerative diseases related to ageing. The Department of Health in the United Kingdom (UK) has set out a national strategy to address the needs of people with dementia and their carers. One of its key aims is to develop a range of services that meet the needs of patients and their family over time as the illness progresses [1].

To help implement this national dementia strategy, a digital initiative called '*My House of Memories*' was launched to involve people with dementia and their carers in the design of a mobile application that would allow them to share memories together [2]. It is hoped that this form of reminiscence therapy will help improve patients' mood, cognition and functional ability as well as reduce caregiver strain. The aim of this study is to explore the barriers experienced by all participants during the co-design of the '*My House of Memories*' app, to ensure that the future co-production of mobile technology is more effective.

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2. Methods

The study adopted a qualitative exploratory case study design. An in-depth focus (n=10) and interviews (n=6) with people involved in the co-design of the '*My House of Memories*' app was held between March and September 2015. This included four dementia patient-carer dyads, an occupational therapist, a project manager and a software engineer. Data was thematically analysed using the framework approach [3].

3. Results

The lack of digital literacy knowledge and skills among people with dementia and their carers was the first factor that changed how the mobile application was co-designed. It took time for these individuals to become familiar with using tablet computers as well as grasping the technical language the software development team. Other issues that affected co-production were inaccurate perceptions of how people with dementia or carers would use mobile technology which meant many initial design ideas had to be scrapped or significantly changed. Some patients with dementia and their carers also held negative attitudes towards technology which limited their participation in designing the mobile app. Furthermore, people who were in the later stages of dementia struggled to take part in the workshops and compromises also had to be made to the design and functionality of the mobile app as it was impossible to incorporate everyone's ideas.

4. Discussion

While co-designing technology can help create tailored mobile apps that meet the specific needs of patients and carers, certain barriers can slow down and change the process. Developing digital applications with people with dementia and their carers needs to be well thought out, planned and executed to address poor attitudes, inaccurate perceptions, lack of digital literacy knowledge and skills and to ensure any compromises made in the design are justified and add value for the majority of users. More research into designing digital services with patients and carers should be done to uncover the complexities involved and to help develop a robust methodology that is theoretically grounded.

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